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Progress in Community Health Partnerships: Research, Education, and Action, Volume 14, Issue 4, Winter 2020, pp. 461-470 (Article)

Published by Johns Hopkins University Press
DOI: https://doi.org/10.1353/cpr.2020.0051

Building Bridges: Describing a Process for Indigenous Engagement in Epidemiology

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Submitted 21 December 2018, revised 15 November 2019, accepted 14 April 2020

Abstract

Background: Processes for epidemiology embedded with Indigenous methodology are needed. Building Bridges was developed to engage Indigenous peoples in epidemiology to address health issues relevant to them.

Objectives: We describe our process for meaningfully engaging Indigenous leaders and peoples living with human immunodeficiency virus (HIV) in epidemiology research.

Methods: As a community-based research (CBR) project, Indigenous methodologies and leadership ensured the quality and relevance of findings. Study phases included 1) advisory board formation, 2) recruitment, 3) research question identification, 4) data analysis from the Canadian HIV Observational Cohort (CANOC) collaboration, 5) data interpretation and contextualization, and 6) knowledge translation and exchange.

Lessons Learned: Support and guidance from Indigenous team members, Spiritual Leaders and Elders along with meaningful relationships with allied academic researchers were pivotal. Expertise and lived experiences in Indigenous culture, HIV, epidemiology and services enabled multidirectional learning.

Conclusions: Building Bridges' success hinged on ongoing co-learning and engagement of Indigenous peoples, service providers and researchers.

Keywords

Indigenous health, Epidemiology, HIV/AIDS, Cohort studies, Methodology

There is a history of unethical research conducted on First Nations, Métis and Inuit Peoples (Indigenous Peoples) in Canada, where Indigenous Peoples have experienced grievances, including absence of consent, limited access to data, lack of involvement in research question development and study design, and lack of acknowledgement as research contributors.[1] Epidemiology employs a deficit-based framework by portraying Indigenous peoples as sick, disadvantaged and incompetent.[2,3] The deficit-based framework can be challenged by working collaboratively with communities to focus on their strengths, building their capacity and involving community members as partners in endeavors to reduce disparities, including research.[2,3] There is a growing number of epidemiology and health research studies conducted collaboratively with Indigenous peoples and communities as research partners, from research development to research dissemination.[4,5] These studies may still identify problems or needs (i.e., deficit-based), but at least focus on what Indigenous people desire researching making the data more meaningful and useful to them. Indigenous people are also increasingly becoming decision-makers throughout the research process which includes for example interpreting findings to ensure it does not further stigmatize them.[4,5]

Within epidemiology, restricted access to data, failure to meaningfully involve Indigenous partners and the small (but growing) number of Indigenous researchers with formal epidemiology training limits Indigenous community engagement. In Canada, Indigenous Peoples have disproportionately higher rates of HIV prevalence and incidence.[6] Colonialism has been recognized as a determinant of health but a broader understanding and application of Indigenous Peoples' determinants of health is needed.[7–9] Trauma, racism, HIV stigma, and colonialism impact how HIV affects Indigenous communities.[10,11] Furthermore, certain Indigenous populations, particularly those living in northern and rural areas in Canada, have limited access to primary healthcare and are at risk of receiving poorer HIV-related care.[12–14] These factors suggest that Indigenous Peoples have unique needs and unaddressed research questions. It is important to reconcile how Indigenous worldviews and epidemiology can work together to meet the needs of and improve Indigenous Peoples' health.[15]

The Building Bridges research project was developed to make epidemiology research more inclusive of Indigenous peoples and communities. Building Bridges was a collaboration between Indigenous and allied academic researchers, Indigenous community members, and the CANOC Collaboration, in which Indigenous peoples affected by HIV engaged in epidemiology research. We have defined allied individuals as those who are working with and for Indigenous people on topics of interest to Indigenous people who are building relationships that are trusting and that has been sustained over time permitting future work opportunities. The objectives were to 1) develop a CBR process in epidemiology embedded with Indigenous methodologies; 2) implement this process in two Canadian cities; and 3) identify and answer epidemiology questions pertaining to HIV and Indigenous peoples in Canada using CANOC data. This article describes the process that guided Building Bridges and discusses key lessons learned.

RESEARCH PROCESS

Study Design and Methodology

The Building Bridges research grant emanated from the need to establish a research process to make epidemiology data and research findings more accessible to Indigenous individuals and communities whose personal health information are included in cohorts. We described and implemented our process in Toronto and Vancouver, Canada answering research questions using the CANOC collaboration data, a multiprovincial database of clinical and antiretroviral therapy data on people living with HIV.[16] The CANOC coordinating site is located in Vancouver.

A critical aspect of our study design was to engage Indigenous people in the research process. Our process developed iteratively, and changes made valued Indigenous methodologies. Evans et al. described Indigenous methodologies "as research by and for Indigenous people using techniques and methods drawn from the traditions and knowledges of those people."[17] Our Indigenous methodologies consisted of prioritizing Indigenous worldviews, knowledge, histories, and realities as well as privileging Indigenous voices, peoples, and lands. For example, ceremony led by Knowledge Carriers was a key component of the process. Knowledge Carrier is an umbrella term for Indigenous healers, cultural teachers, grandmothers, or Elders for example. Cultural activities included ceremonies, meals, teachings, medicines (i.e., tobacco, sage, cedar, and sweetgrass), smudging, and tobacco offerings. In Toronto, a dream story and drumming were included and in Vancouver, medicine pouches and songs. Given the localized nature of Indigenous knowledges, both cities included regionally appropriate ceremonies. Before any research activities, the meeting facilitators in each city met with the local Knowledge Carriers to determine how local Indigenous knowledges and practices could inform the process.

Description of a Multiphase Research Process

A retrospective look at the research process identified six phases: 1) establishing local advisory committees, 2) recruitment of Indigenous people living with HIV for advisory committees, 3) research question development, 4) data analysis, 5) data interpretation, and 6) knowledge translation and exchange. In Toronto, meetings were held as the research unfolded, when substantial progress had been made during a research step and the team needed to be updated. A similar process and timeline were followed in Vancouver. A maximum of five in-person meetings including the final gathering were held, two teleconference calls, and several emails between July 2013 and March 2015.

Phase 1: Local Advisory Committees. We established two advisory committees including research team members and Indigenous stakeholders. The committee guided subsequent phases and informed the application of Indigenous methodologies to epidemiology research. The Indigenous stakeholders had long-standing (years to decades) research relationships with the research team members. CBR principles[18] were followed to varying degrees by the Indigenous stakeholders given their time commitments, interest in the project, and desired roles to hold in research studies. Meaningful and trusting relationships existed among members of the advisory committee who were largely Indigenous people from across Canada.

One advisory committee was formed in Toronto, and the other in Vancouver. In Toronto, the committee included two Indigenous agency representatives, four Indigenous scholars, two Indigenous persons with experience accessing and providing front-line services, a Knowledge Carrier, and an allied scholar. In Vancouver, the committee included two Indigenous agency representatives, two provincial HIV agency representatives, an Elder, two Indigenous scholars and two allied scholars. Efforts were made to seek Indigenous expertise on the advisory committees at each site. Each site hired an Indigenous Research Assistant who had worked with Indigenous agencies and was known by the community.

The advisory committee formulated during an in-person meeting guiding principles for creating culturally safe spaces (Appendix 1), statements on inclusivity (Appendix 2), and considerations for the inclusion of Indigenous knowledges in the research process (Appendix 3), as well as discussion on recruitment strategies. The recruitment and engagement of Indigenous people living with HIV was dependent on establishing a culturally safe and inclusive space of different intersecting identities and Indigenous knowledges.

Phase 2: Recruitment. Through informal and formal networks, advisory committee members and RAs recruited Indigenous people living with HIV as study participants to be part of the advisory committee. Advisory committee members who chose to participate in the gatherings provided written informed consent and the objectives of the study were rearticulated. Indigenous agency representatives on the committee who were trusted by Indigenous persons living with HIV, and co-investigators working with community agencies and Indigenous health research connected potential participants to the RAs. Recruitment strategies included word-of-mouth and distributing flyers or cards with meeting dates and Research Assistant contact information. The study participants reflected the Indigenous population included in CANOC as they were Indigenous people living with HIV and on antiretroviral therapy. It was critical to include their perspectives in the research process. In keeping with the guiding principles of our work, the study participants, Indigenous people living with HIV, became valued research team members on the advisory committees.

In Vancouver, the advisory committee recommended limiting recruitment to Indigenous women living with HIV because creating a safe space for discussion for this population was identified as a local need. Seven Indigenous persons were recruited. Two community outreach nurses joined the research activities and provided support for some of the Indigenous women living with HIV with whom they had longstanding relationships. In Toronto, we recruited both Indigenous women and men including a youth and members of the two-spirit community for a total of four individuals.

Phase 3: Research Question Development. Indigenous people living with HIV who were recruited to the project joined advisory committee members to form one research team in each city. In Toronto, there were in-person gatherings, which took the form of Sharing Circles in this phase. These circles, similar to focus groups captured experiences through group discussions, but included ceremony and other local Indigenous protocols.[19–21] In Vancouver, the committee did not feel that the gatherings would adhere to Sharing Circle protocols for all participants because they were from

Indigenous groups with different Sharing Circles protocols. To respect everyone's teachings regarding Sharing Circles, they established their own protocols to follow in the gatherings which they decided to name Voices of Wisdom.

At the first Sharing Circle and Voices of Wisdom gathering, committee members continued building relationships with each other. Committee members with expertise in epidemiology provided introductory teachings on epidemiology and statistics, and an overview of CANOC. During the second gatherings, committee members continued their discussion on HIV and health-related issues that were of concern to Indigenous people living with HIV. With assistance of committee members, the issues were formulated into research questions that could be answered with existing CANOC data. In Toronto, several emails and two teleconference calls were held to further refine the research questions. They developed research questions focused on a comparison of rates of HIV virologic suppression, treatment interruption, and mortality between Indigenous Peoples and other ethnicities.

Phase 4: Data Analysis. Each advisory committee formulated research questions into a CANOC data request form and CANOC statisticians performed data analyses. CANOC statisticians were accessible to all research team members to further discuss the analysis plan but mostly corresponded with an Anishinaabe (E.N.) and a Mi'kmaw research team member (A.B.) with expertise in epidemiology.

Phase 5: Data Interpretation and Knowledge Translation and Exchange. At the Sharing Circle and Voices of Wisdom gathering, the statisticians presented the findings from the data analysis to their respective research teams. Members of each research team provided Indigenous perspectives and discussed the meaning of the findings, implications for their communities and how to share the findings.

Integrated and end-of-grant knowledge translation strategies were practiced throughout this project. During each phase, knowledge sharing occurred among team members with expertise shaped by their lived experiences as Indigenous people, service users, health and social service providers, or community and academic researchers.

Our findings included information on our research process and results from the CANOC analyses. Our first end-of-grant knowledge translation strategies activity was to hold Indigenous feasts in both cities where we shared the findings, thanked everyone involved, and commemorated the completion of study activities. Advisory committee members and research team members invited friends, family, and community members, and Indigenous agency representatives invited colleagues with an interest in our findings. The Toronto and Vancouver committees each prepared a video of their respective findings to exchange with one another. By means of Indigenous gift-giving, Toronto and Vancouver committee members exchanged gifts such that everyone received a symbolic coin and a cedar bracelet to honor their contributions. In Toronto, the committee members honored the participants during a feast. They received a sweet grass braid, a blanket, and a certificate acknowledging the time they dedicated to the project. All Vancouver committee members received a blanket and certificate acknowledging their role.

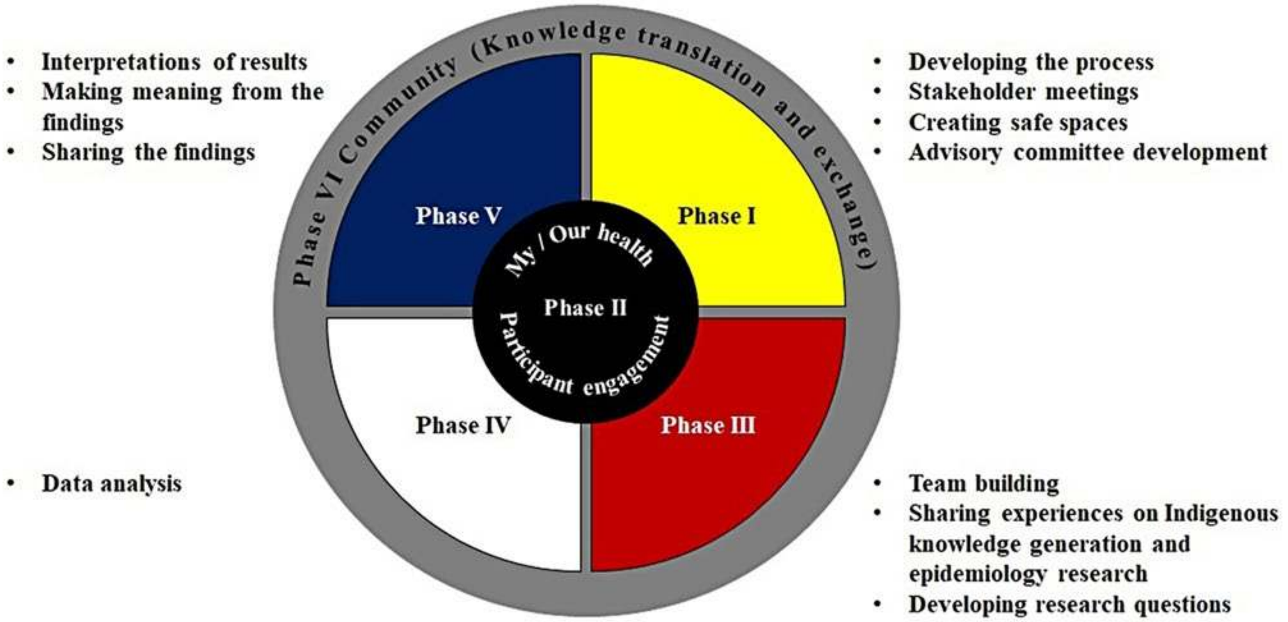
In addition, various research team members (Indigenous and allied) prepared abstracts for scientific meetings and conferences and participated in manuscript writing. Several Indigenous people living with HIV presented study findings, and many are co-authors on the published manuscripts on the CANOC analysis.[22–24]

Research Ethics

This study was reviewed and approved by the Research Ethics Boards at Women's College Research Institute and Providence Health Care/University of British Columbia. The Tri-Council Policy Statement on Research Involving the First Nations, Inuit and Métis Peoples of Canada; Ownership, Control, Access and Possession principles; and the Meaningful Involvement of People Living with HIV/AIDS principles also guided the research.[1,25–27]

RESULTS

We respectfully engaged Indigenous peoples in all aspects of our study, creating strong community investment into and ownership of the work. This collaboration led to the Building Bridges Process for Indigenous Engagement in Epidemiology (Figure 1). We used the medicine wheel to depict the phases required in our process, which was aligned with health concepts defined by our advisory committee consisting of diverse First Nation backgrounds. The following dimensions of health were described: Phase I—emotional (e.g., inter-connectedness,



- Interpretations of results
- Making meaning from the findings
- Sharing the findings

- Developing the process
- Stakeholder meetings
- Creating safe spaces
- Advisory committee development

- Data analysis

- Team building
- Sharing experiences on Indigenous knowledge generation and epidemiology research
- Developing research questions

Figure 1. Building Bridges Process for Indigenous Engagement in Epidemiology as depicted through the Medicine Wheel

The phases required in our process were aligned with concepts of health defined by our advisory committee, largely of diverse First Nation backgrounds. The dimensions of health included Phase I—emotional (e.g., inter-connectedness, connecting the heart and head, determining the process), Phase II—my/our health (e.g., engaging the local community), Phase III—physical (e.g., inter-relationships, building relationships takes time, relating to issues that formed research questions), Phase IV—mental (e.g., balance and respect of the knowledges, analyzing the data), and Phase V—spiritual (e.g., wholeness, using the local knowledge to interpret the findings, and sharing the findings.

connecting the heart and head, determining the process), Phase II—my/our health (e.g., engaging the local community), Phase III—physical (e.g., face-to-face relationship building), Phase IV—mental (e.g., balance and respect of the knowledges, analyzing the data), and Phase V—spiritual (e.g., wholeness, using the local knowledge to interpret the findings, and sharing the findings). Although the medicine wheel is not shared among all Indigenous groups in Canada, the circle incorporates concepts of health widely believed by Indigenous societies (e.g., Métis, Inuit, and Maori) around the world: holism, balance, and interconnectedness among the dimensions of health.[28] Thus, this depiction of a research process can be adapted by other Indigenous groups to create their own research process that relates to their concepts of health.[28]

Lessons Learned

Upon reflecting on the Building Bridges project and research process, three lessons about developing collaborative relationships, multidirectional learning, and team building emerged.

Lesson 1: Indigenous Leadership, Spiritual Leaders and Elders' Support and Guidance, and Meaningful Relationships with Allied Academic Researchers Were Pivotal. Key aspects of our research process included building trust and meaningful relationships among team members. Relationships were cultivated by spending time together in face-to-face environments, talking informally and formally, and sharing stories, as well as respecting each other and the unique perspectives brought forward. We also consciously had discussions on equitable access of different aspects of research such as the language used during meetings. We discussed tensions that came with merging different epistemological approaches,[29] for example Indigenous methodologies and epidemiology. We navigated these tensions through ongoing reflection and open and consistent communication. We honored the diverse experiences that all members brought to the research, the relationships they formed with each other, and with Indigenous ways of knowing and doing.

Bringing a Knowledge Carrier and Elder into the process allowed for the honoring of protocols and co-learning of how to do “research in a good way,” which includes providing local context and history and taking on ceremonial roles, for example.[30] It enabled the team members to strive to understand how each member might perceive epidemiology research and what it means to do such research in an Indigenous way. This contributed to creating a safe place for the research. In addition, forming separate committees at each site acknowledged the cultural diversity among Indigenous Peoples in Canada, enabled local expertise to inform the study, and allowed for in-person meetings and relationship building.

Lesson 2: Diverse Lived Experience and Expertise in Indigenous Culture, HIV Research, Epidemiology and Services Enabled Multidirectional Learning. Team members and participants engaged in the Sharing Circles and Voices of Wisdom gatherings in non-hierarchical way. Gatherings facilitated co-learning, relationship building and the deconstruction of barriers, particularly between academia and community, and physicians and patients. Some participants appreciated that some of the academic participants were also care providers that had valuable clinical experiences to share. They also recognized that the academics became students, learning about traditions and protocols that were new to them. Relationships were fostered among community members, such that Indigenous peers with more research experience mentored those with less experience.

Lesson 3: Frequent Engagement Facilitated Team Building. Team building within and between the two sites required frequent engagement. Communication through in-person meetings at a central location, teleconferences, and emails facilitated team cohesion. However, despite attempts to maintain frequent engagement, there were periods where team members were not involved for several months (e.g., during data analysis) and this contributed to attrition. In addition, limited email or phone access was a barrier for some.

DISCUSSION

The process enacted in our epidemiology study allowed us to enjoy the benefits of CBR principles[31] and Indigenous methodologies throughout our study including analysis and interpretation of quantitative data. Using CBR, we were able to establish a collaborative research process between individuals of intersecting identities, who were largely Indigenous, that valued diverse knowledge systems including Indigenous ways of knowing and doing. This has been observed in other epidemiology studies engaging different communities.[32]

Our process enabled us to generate research questions on areas of concern to Indigenous people living with HIV.[22–24] This led to greater interest in the findings and investment in knowledge sharing. We were also able to support the stories of Indigenous people living with HIV with data from CANOC that mirrored their observations. In one of the published manuscripts, several team members’ stories were used to contextualize population-level aggregate data.[24] In addition, many of the team members living with HIV found the experience to be both self-determining and enlightening. The realization they were personally a part of the data made the statistics emotionally impactful and motivating.

Indigenous People’s engagement in epidemiology studies has been gaining more widespread attention in recent years with differing degrees of Indigenous engagement from being consulted with to having a leadership role.[33–35] Linking epidemiology methods with approaches centering colonialism as a determinant of health and critiquing these methods to improve the accuracy and acceptability of Indigenous health statistics are ways that epidemiology can be used to advocate for Indigenous health issues.[33] Data governance through collaborative research allows Indigenous communities to use data to understand and address relevant issues.[36] Frameworks for working with Indigenous health administrative data have been developed, such as that articulated by the Institute for Clinical Evaluative Sciences which provides guidance around ethical relationships, data governance, methodology and approaches and using evidence to build policies and programs.[34] This frameworks shares features and principles with our process and other Indigenous-engaged epidemiology research processes.[33–35,37,38] However, the process we describe focuses on supporting the direct involvement of Indigenous community members whose data are included in databases and provides more details on how Indigenous ceremony and protocols have been used. The former provides crucial dialogue on Indigenous stewardship and governance of data and the latter enables researchers to visualize how they might meaningfully engage Indigenous team members in their work.

In Building Bridges, we also encountered several challenges. Some Indigenous participants found the findings triggering as they brought up feelings of despair when they learned that outcomes in their communities were worse than those in non-Indigenous communities or when they reflected that among Indigenous people living with HIV, they may be in a better health or social situations. Ensuring the availability of ceremony, emotional support, and spiritual support for team members both during and after the research mitigated the above potential harms. For future studies, peer support in the form of a buddy system can also be considered.

Our process can be used to guide future epidemiology research that aims to meaningfully engage Indigenous peoples. Furthermore, we have developed appendices outlining creation of safe spaces, inclusivity, and use of Indigenous methodology which can be used as guiding principles for others engaging in research with Indigenous team members. Our process is being used to engage additional Indigenous communities in directing CANOC analyses and there are plans to adopt this to be used in health administrative data.

Limitations

We used our process for Indigenous engagement in epidemiology in Toronto and Vancouver, so it does not necessarily reflect an approach that would meaningfully involve all Indigenous Peoples in all types of epidemiology research. Local context, history, and protocols are necessary to inform the use of our process in other settings. In addition, Indigenous populations in rural areas may differ from those in urban areas and our process has not been used in a rural setting.

CONCLUSIONS

We developed our Building Bridges process for Indigenous engagement in epidemiology to ensure that epidemiological methods incorporate Indigenous cultural practices and meaningfully engage Indigenous people living with HIV research. Our process included gatherings and ceremony led by Indigenous leaders and Knowledge Carriers. We demonstrated how a collaborative approach could be used to engage Indigenous Peoples in epidemiology research. It may be a way to mitigate some of the mistrust among Indigenous communities, academic researchers, and non-Indigenous people that stems from injustices and ethical violations occurring in the context of epidemiology research. Our process can also be applied to other research fields involving Indigenous Peoples. As this manuscript was being developed, one Indigenous co-author summarized the importance of this work: “I think what we did was unique, and it set a standard. If you want us to come to the table, invite us from the beginning. Don’t just research us. Involve us.”

ACKNOWLEDGMENTS

The authors thank the stewards of the territory of the Mississauga of the New Credit and the Musqueam and Squamish Nations who graciously allowed our CIHR catalyst grant meetings to be held on their land. We also would like to acknowledge our ancestors and relationships with the animals, the water, air, and the plants of this land. We also thank Knowledge Carrier Wanda Whitebird and Elders Roberta Price and Doris Paul-Xele’milh for their leadership and spiritual guidance throughout the research process. We would also like to thank Two Spirit Elder, Carol Kellman (RN), as well as St. Paul’s Hospital for their support and the use of the All Nation’s Sacred Space. We would also like to thank statisticians, Dr. Janet Raboud and Jamie Younger for their assistance with data analysis and sharing knowledge and statistical methods. In addition, we would like to thank all service providers who work tirelessly on the front lines of the HIV pandemic to meet the social and health care needs of people living with HIV. We would also like to thank Simran Jawanda for all her help editing this article. Thank you to the community members, researchers, clinicians and all experts who are key stakeholders in Indigenous health and played a pivotal role in guiding the discussion. We also wish to acknowledge the women and men living with HIV whose information is contained within the CANOC Collaboration database, which will permit us to ask research questions that will advance our HIV knowledge to improve the lives of those living with HIV. Furthermore, the Ontario Aboriginal HIV/AIDS Strategy, 2-Spirited People of the 1st Nations and the Canadian Aboriginal AIDS Network were key partners in our work.

Finally, we would like to thank all of the CANOC collaborators. The CANOC Collaborative Research Centre includes: CANOC Principal Investigator: Robert Hogg (British Columbia Centre for Excellence in HIV/AIDS, Simon Fraser University), site Principal Investigators: Ann N. Burchell (Ontario HIV Treatment Network, University of Toronto, OHTN Cohort Study [OCS]), Curtis Cooper (University of Ottawa, OCS), Deborah Kelly (Memorial University of Newfoundland), Marina Klein (Montreal Chest Institute Immunodeficiency Service Cohort, McGill University), Mona Loutfy (University of Toronto, Maple Leaf Medical Clinic, OCS), Nima Machouf (Clinique Médicale l'Actuel, Université de Montréal), Julio Montaner (British Columbia Centre for Excellence in HIV/AIDS, University of British Columbia), Janet Raboud (University of Toronto, University Health Network, OCS), Chris Tsoukas (McGill University), Stephen Sanche (University of Saskatchewan), Alexander Wong (University of Saskatchewan) Co-Principal Investigators: Tony Antoniou (St. Michael's Hospital, University of Toronto, Institute for Clinical Evaluative Sciences), Ahmed Bayoumi (St. Michael's Hospital, University of Toronto), Mark Hull (British Columbia Centre for Excellence in HIV/AIDS), Bohdan Nosyk (British Columbia Centre for Excellence in HIV/AIDS, Simon Fraser University) Co-Investigators: Angela Cescon (Northern Ontario School of Medicine), Michelle Cotterchio (Cancer Care Ontario, University of Toronto), Charlie Goldsmith (Simon Fraser University), Silvia Guillemi (British Columbia Centre for Excellence in HIV/AIDS, University of British Columbia), P. Richard Harrigan (British Columbia Centre for Excellence in HIV/ AIDS, University of British Columbia), Marianne Harris (St. Paul's Hospital), Sean Hosein (CATIE), Sharon Johnston (Bruyère Research Institute, University of Ottawa), Claire Kendall (Bruyère Research Institute, University of Ottawa), Clare Liddy (Bruyère Research Institute, University of Ottawa), Viviane Lima (British Columbia Centre for Excellence in HIV/AIDS, University of British Columbia), David Marsh (Northern Ontario School of Medicine), David Moore (British Columbia Centre for Excellence in HIV/ AIDS, University of British Columbia), Alexis Palmer (British Columbia Centre for Excellence in HIV/AIDS, Simon Fraser University), Sophie Patterson (British Columbia Centre for Excellence in HIV/AIDS, Simon Fraser University), Peter Phillips (British Columbia Centre for Excellence in HIV/AIDS, University of British Columbia), Anita Rachlis (University of Toronto, OCS), Sean B. Rourke (University of Toronto, OCS), Hasina Samji (British Columbia Centre for Excellence in HIV/AIDS), Marek Smieja (McMaster University), Benoit Trottier (Clinique Médicale l'Actuel, Université de Montréal), Mark Wainberg (McGill University, Lady Davis Institute for Medical Research), Sharon Walmsley (University Health Network, University of Toronto) Collaborators: Chris Archibald (Public Health Agency of Canada Centre for Communicable Diseases and Infection Control), Ken Clement (Canadian Aboriginal AIDS Network), Fred Crouzat (Maple Leaf Medical Clinic), Monique Doolittle-Romas (Canadian AIDS Society), Laurie Edmiston (Canadian Treatment Action Council), Sandra Gardner (OHTN, University of Toronto, OCS), Brian Huskins (Canadian Treatment Action Council), Jerry Lawless (University of Waterloo), Douglas Lee (University Health Network, University of Toronto, ICES), Renée Masching (Canadian Aboriginal AIDS Network), Stephen Tattle (Canadian Working Group on HIV & Rehabilitation), Alireza Zahirieh (Sunnybrook Health Sciences Centre) Analysts and Staff: Claire Allen (Regina General Hospital), Stryker Calvez (SHARE), Guillaume Colley (British Columbia Centre for Excellence in HIV/AIDS), Jason Chia (British Columbia Centre for Excellence in HIV/AIDS), Daniel Corsi (The Ottawa Hospital Immunodeficiency Clinic, Ottawa Hospital Research Institute), Louise Gilbert (Immune Deficiency Treatment Centre), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Alia Leslie (British Columbia Centre for Excellence in HIV/ AIDS), Lucia Light (OHTN), David Mackie (The Ottawa Hospital), Costas Pexos (McGill University), Susan Shurgold (British Columbia Centre for Excellence in HIV/AIDS), Leah Szadkowski (University Health Network), Chrissi Galanakis (Clinique Médicale L'Actuel), Ina Sandler (Maple Leaf Medical Clinic), Benita Yip (British Columbia Centre for Excellence in HIV/AIDS), Jaime Younger (University Health Network), and Julia Zhu (British Columbia Centre for Excellence in HIV/AIDS).

COMPETING INTERESTS

M.H. is the Nominated Principal Investigator of the CIHR Catalyst Grant that supported the research activities of the project. S.G., E.B., E.B., K.B., and W.B. were paid from the grant as research assistants or Knowledge Carriers.

Financial disclosure

CANOC is funded by the Canadian Institutes of Health Research (CIHR) through a Centres for HIV/AIDS Population Health and Health Services Research Grant [CIHR 711314], Operating Grants HIV/AIDS Priority Announcement [CIHR 711310] and Population and Public Health [CIHR 711319], and by the CIHR Canadian HIV Trials Network (CTN 242). Building Bridges is supported by a CIHR Catalyst Grant. ACB was supported by a CIHR Fellowship Award. All authors read and approved the final version of the manuscript.

REFERENCES

1. Schnarch B. Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. Int J Indig Health. 2004;1(1):80–95.
2. Pyett P, Waples-Crowe P, van der Sterren A. Challenging our own practices in Indigenous health promotion and research. Health Promot J Austr. 2008;19(3):179–83.
3. Tobias JK, Richmond CA, Luginaah I. Community-based participatory research (CBPR) with indigenous communities: Producing respectful and reciprocal research. J Empir Res Hum Res Ethics. 2013;8(2):129–40.
4. Boffa J, King M, McMullin K, Long R. A process for the inclusion of Aboriginal People in health research: Lessons from the Determinants of TB Transmission project. Soc Sci Med. 2011;72(5):733–8.
5. Naqshbandi M, Harris SB, Macaulay AC, Comeau J, Piche J, Montour-Lazare D. Lessons learned in using community-based participatory research to build a national diabetes collaborative in Canada. Prog Community Health Partnersh. 2011;5(4):405–15.
6. Public Health Agency of Canada. Summary: Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets, 2016. Ottawa: Public Health Agency of Canada; 2018.
7. de Leeuw S, Lindsay N, Greenwood M. Introduction: Rethinking determinants of Indigenous peoples' health in Canada. In: Greenwood M, de Leeuw S, Lindsay N, Reading C, editors. Determinants of Indigenous Peoples Health in Canada: Beyond the Social. Toronto, Ontario: Canadian Scholars' Press; 2015. p. xi–xxviii.
8. Nowgesic E. Addressing HIV/AIDS among Aboriginal People using a health status, health determinants and health care framework: A literature review and conceptual analysis. Canadi J Aborig Community Based HIV/AIDS Res. 2010;3:35–46.
9. Czyzewski K. Colonialism as a broader social determinant of health. Int Indig Policy J. 2011;2(1):1–14.
10. Duff P, Bingham B, Simo A, Jury D, Reading C, Shannon K. The 'stolen generations' of mothers and daughters: Child apprehension and enhanced HIV vulnerabilities for sex workers of Aboriginal ancestry. PLoS One. 2014;9(6):e99664.
11. Negin J, Aspin C, Gadsden T, Reading C. HIV Among Indigenous peoples: A review of the literature on HIV-related behaviour since the beginning of the epidemic. AIDS Behav. 2015;19(9):1720–34.
12. Lima VD, Kretz P, Palepu A, Bonner S, Kerr T, Moore D, et al. Aboriginal status is a prognostic factor for mortality among antiretroviral naive HIV-positive individuals first initiating HAART. AIDS Res Ther. 2006;3:14.
13. Miller CL, Spittal PM, Wood E, Chan K, Schechter MT, Montaner JS, et al. Inadequacies in antiretroviral therapy use among Aboriginal and other Canadian populations. AIDS Care. 2006;18(8):968–76.
14. Shah BR, Gunraj N, Hux JE. Markers of access to and quality of primary care for aboriginal people in Ontario, Canada. Am J Public Health. 2003;93(5):798–802.
15. Nowgesic E. What does it mean to have an Aboriginal Health Epidemiology Model? Toronto: Building Bridges Final Toronto Gathering; 2015.
16. Palmer AK, Klein MB, Raboud J, Cooper C, Hosein S, Loutfy M, et al. Cohort profile: The Canadian Observational Cohort collaboration. Int J Epidemiol. 2011;40(1):25–32.
17. Evans M, Hole R, Berg L, Hutchinson P, Sookraj D. Common insights, differing methodologies: Toward a fusion of Indigenous methodologies, participatory action research, and white studies in an urban Aboriginal research agenda. Qualitative Inquiry. 2009;15(5):893–910.
18. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. Annu Rev Public Health. 1998;19: 173–202.
19. Lavallée LF. Practical application of an Indigenous research framework and two qualitative Indigenous research methods: Sharing circles and Anishnaabe symbol-based reflection. Int J Qual Methods. 2009;8(1):21–40.
20. Poff DC. The importance of story-telling: Research protocols in aboriginal communities. J Empir Res Hum Res Ethics. 2006; 1(3):27–8.
21. Rothe JP, Ozegovic D, Carroll LJ. Innovation in qualitative interviews: "Sharing Circles" in a First Nations community. Inj Prev. 2009;15(5):334–40.
22. Benoit AC, Younger J, Beaver K, Jackson R, Loutfy M, Masching R, et al. Increased mortality among Indigenous persons in a multisite cohort of people living with HIV in Canada. Can J Public Health. 2017;108(2):e169–e75.
23. Benoit AC, Younger J, Beaver K, Jackson R, Loutfy M, Masching R, et al. A comparison of virological suppression and rebound between Indigenous and non-Indigenous persons initiating combination antiretroviral therapy in a multisite cohort of individuals living with HIV in Canada. Antivir Ther. 2017;22(4):325–35.
24. Jaworsky D, Ranville F, Nicholson V, Price R, Kellman C, Benson E, et al. on behalf of the Building Bridges Team and the Canadian Observational Cohort (CANOC) collaboration. Antiretroviral therapy treatment interruption among Indigenous Peoples living with HIV in Canada—a Building Bridges study guided by community. Journal of Indigenous HIV Research. 2018;9:22–37.

25. Greene S. Peer research assistantships and the ethics of reciprocity in community-based research. J Empir Res Hum Res Ethics. 2013;8(2):141–52.
26. Government of Canada. TCPS 2 - Chapter 9: Research involving the First Nations, Inuit and Métis Peoples of Canada, 2014 [cited 2017 May 30]. Available from: http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/
27. First Nations Centre. OCAP: Ownership, Control, Access and Possession, 2007 [cited 2017 Jul 25]. Available from: http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf
28. Richmond CAM, Ross NA, Bernier J. Exploring Indigenous concepts of health: The dimensions of Metis and Inuit health. Aboriginal Policy Research Consortium International (APRCi). 2007:3–16.
29. Whitley MA, Massey WV. Navigating tensions in qualitative research: Methodology, geography, personality and beyond. Qual Res Sport Exerc Health. 2018;10(5):543–54.
30. Flicker S, O'Campo P, Monchalin R, Thistle J, Worthington C, Masching R, et al. Research done in "A Good Way": The importance of Indigenous Elder involvement in HIV community-based research. Am J Public Health. 2015;105(6):1149–54.
31. Strand K, Marullo S, Cutforth NJ, Stoecker R, Donohue P. Principles of best practice for community-based research. Michigan Journal of Community Service Learning. 2003;9(3).
32. Sapienza JN, Corbie-Smith G, Keim S, Fleischman AR. Community engagement in epidemiological research. Ambul Pediatr. 2007;7(3):247–52.
33. Prussing E. Critical epidemiology in action: Research for and by indigenous peoples. SSM Popul Health. 2018;6:98–106.
34. Pyper E, Henry D, Yates EA, Mecredy G, Ratnasingham S, Slegers B, et al. Walking the Path Together: Indigenous health data at ICES. Healthc Q. 2018;20(4):6–9.
35. Walker JD, Rowe R, Jones CR. Describing the process of ethical conduct of research in an Ontario-wide First Nations diabetes research project. CMAJ. 2018;190(Suppl):S19–S20.
36. Rainie SC, Schultz JL, Briggs E, Riggs P, Palmanteer-Holder NL. Data as a strategic resource: Self-determination, governance, and the data challenge for Indigenous nations in the United States. Int Indig Policy J. 2017 8(2):1–29.
37. Smylie J, Anderson M. Understanding the health of Indigenous peoples in Canada: Key methodological and conceptual challenges. CMAJ. 2006;175(6):602.
38. Bruhn J. Identifying useful approaches to the governance of indigenous data. Int Indig Policy J 2004;5 (2):1–32.